



# **contact**

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## **THE HOSPICE MOVEMENT**



**PROVIDING COMPASSIONATE AND  
COMPETENT CARE FOR THE DYING**

## INTRODUCTION

The goal of scientific medicine is to save lives. When it becomes clear that a patient is going to die, those of us trained as "scientific" practitioners feel that we have failed. This can lead to all kinds of behaviour that is helpful neither to our patients nor to ourselves. We deny adequate medicinal relief to patients in pain, with the irrational excuse that they may become addicted. We call on technological wizardry to stall the inevitable, often prolonging death rather than life and robbing persons of their human dignity.

During my years working with aboriginal Americans, I commonly witnessed a patient dying at home, surrounded by family, friends, children, animals, and all that he or she held dear. After the sheet was drawn over the face, someone would often say, "He died well." Most non-western cultures perceive death as an important part of life, necessary to complete the circle of life. We have much to learn from this outlook.

The international hospice movement is working to restore a competent and compassionate way of dealing with death. St. Christopher's Hospice in London has been a guiding light in this movement, both in medical research and in its example of excellence in caring.

When I first entered St. Christopher's Hospice, I was vaguely expecting muffled sounds of wailing coming from shadowy, sombre wards. Instead there were sounds of laughter from rooms decorated with brightly coloured balloons and crayon drawings. Children and grandchildren were playing games with patients in some rooms. In others, nurses were sitting at bedsides, chatting with patient and relatives—in contrast to the usual rushing from hospital bed to

bed with a tray of medications. In a large-windowed community room, a pile of burnt candles beside a few remnants of cake remained in evidence of a birthday party. These activities were not to mask the gloom of impending death but an indication of an atmosphere that allows patients and their families to express their feelings fully.

Not only patients but staff benefit from the hospice atmosphere. I met one nurse who said he had found there what he really went into nursing for—the time and support to really care for patients.

Although the hospice attracts two to three thousand visitors a year, its founder, Dame Cicely Saunders gave me a personally guided tour, as though I were the first. It is this genuine compassion and respect for individuals that has brought out the best in staff, students, and patients and ultimately led to the flowering of this lovely institution.

Dame Cicely has kindly taken time from her very busy routine to share with *Contact* readers the story of her journey in establishing St. Christopher's, in hopes that what she has learned may help dying people and their families around the world.

Dr Saunders tells us that many hospices have adopted a dove as their sign, symbolizing the attempt to "free people's wings" to fly fearlessly toward the horizon. She points out that most important to this work is listening. Perhaps there is a lesson here for us all, even before we are dying.

Dave Hilton

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### COVER

"Holy Ghost" (here reproduced in black and white) by Marian Bohusz-Szyszko, husband of Dame Cicely Saunders, founder of St. Christopher's Hospice.

The dove, with wings freed to fly toward the horizon, has been adopted by many hospices as a symbol of hospice work.

# THE HOSPICE MOVEMENT

by Dame Cicely Saunders\*

## Inspiration

In 1948, when he was 40 years old, David Tasma, a Jewish refugee from Warsaw, died of cancer in a London hospital. As a former nurse and by then a social worker, I visited him almost daily during the last eight weeks of his life. He needed better control of the symptoms of his illness, but still more the chance to talk about his life and his feeling that he had done so little with it. Somehow our conversations gave him hope. He returned quietly and privately to the faith of his fathers and found value and peace.

During our many meetings, we discussed a vision of a place that would be able to help people like him more easily and personally than a busy hospital ward. Upon his death, he left me £500, saying, "I'll be a window in your Home." I believed he had given me a challenge to be open among ourselves and the world.

Once during the moments that we spent together, after I had recited the 23rd Psalm, I suggested that I read more Psalms to him. He said, "No, I only want what is in your mind and your heart." As I thought of this later, I came to believe that people like David should receive care with all the understanding and skills of the mind, together with the friendship of the heart.

David Tasma, who thought he had made no impact on the world, generated the ideas of expert symptom control and caring which stand like two pillars supporting the structure of hospice care.

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\* Dame Cicely Saunders, O.M., D.B.E., F.R.C.P., is the Chairman of St. Christopher's Hospice and widely regarded as the founder of the modern hospice movement.

## The founding

The foundation of St. Christopher's Hospice and, to a large extent, the modern hospice movement dates from the death of this one man—born of his need, his achievement, and his founding gift. Believing that this was a call from God, I set out to learn more about the needs of dying people. After three years working as an evening volunteer in St. Luke's Hospital, London for dying patients, I discussed my plans with the surgeon I was working for during the day. "Go and study medicine," he said. It's the doctors who desert the dying. There's so much more to be learnt about pain. You'll only be frustrated if you don't do it properly and they won't listen to you."

He was right, and so, while continuing to learn as a volunteer, I completed the full medical training course. Then a fellowship enabled me to spend seven years in St. Joseph's Hospice, founded in 1905 for chronically sick and dying patients, developing and researching methods of pain and symptom control, and I was continually learning from the patient's of their fears, longings, and hopes. During this time, we summarized and analyzed the notes of 1100 patient's, with particular concern for pain and its relief. Contact through writing and speaking to many professional audiences showed me how many people realized that understanding and care for the dying were inadequate both in hospital and out in the community. Meeting with people with sad memories of their own underlined the great need for a new look at this field.

## Beginnings

After much travelling, discussion, and reading, it was at last time to bring together all the ideas and hopes and to plan the first modern hospice. It was to be a Christian and a medical foundation

dedicated to care, research, and teaching and to the support of the whole family of the dying cancer patient. Staffed by a multidisciplinary team, it would provide the patient's need for a home as well as in-patient care.

The Christian commitment was expressed simply in the chapel available for Christian worship, but David's challenge to openness was not forgotten, nor his own return to his Jewish faith. The staff, as well as the patients, were to be of various faiths, or none at all. They would be brought together by a conviction of the potential for peace and growth during the latter part of life and to the hope that people may reach their own personal goals. Many of the staff, however, believed that in serving our patients and their families we would be working alongside a God who, because he died and rose again, travels the road of death with all His children. The spiritual "director" of the hospice and later official visitor was the Anglican bishop of the diocese in which St. Joseph's was located. A person of great pastoral gifts, he and other advisers exerted tremendous influence on the character of St. Christopher's.

Earlier research at St. Joseph's and St. Luke's had given us some understanding of the pain our patients would experience, with all its physical, personal, and spiritual anguish and its effect on their families. A patient said, "When I came here you listened. It seemed the pain went while I was talking." Listening would be a primary skill to be developed among the multidisciplinary staff of St. Christopher's, and we would continue to research ways of providing understanding and relief through our experience with the many patients we were to welcome over the years.

### St. Christopher's opens

The work that had been done earlier in St. Joseph's Hospice attracted gifts large and small. With these gifts a new charity was formed, and the hospice of 70 beds (now 78) was built in a suburb of South London. Opened in the summer of 1967, the facility includes four wards for patients with cancer and motor neurone disease and 16 bed/sitting rooms for the frail elderly, often including relatives of the staff or the large team of volunteers.

## History of the hospice movement

Before the fourth century A.D. it was thought unethical to treat a patient with a deadly disease. Doctors feared that in so doing so they risked the penalty for challenging nature and the gods. Then, in response to Jesus' parable that ends with the command, "Inasmuch as you did it to the least of these my brothers you did it to me," there developed many Christian *hospes*, first in the Eastern Mediterranean region, then in Rome, and finally throughout Europe.

The Latin word *hospes* at first signified *host* but later came to mean *stranger*. It also became used to identify a place where pilgrims were welcomed (*hostel* or *hotel*). Since the travellers were often battered and dying, the *hospes* became associated with care for the sick (*hospice* or *hospital*). Hospitals developed along

main roads, offering care for travellers but also for local people in need.

Hospice services came to an abrupt end with the Reformation, when the incurable and dying were consigned to Poor Law institutions. The use of the word *hospice* solely to designate institutions providing care of the dying was by Mme Jeanne Garnier, who founded several hospices in Lyons, France in 1842. The Irish Sisters of Charity opened our Lady's Hospice in Dublin in 1879 and St. Joseph's Hospice in East London in 1905. Three protestant homes for the dying were opened in London in the interim. St. Joseph's Hospice served as both an inspiration and a model for St. Christopher's Hospice, now unquestionably the most well known and the catalyst behind the founding of hundreds around the world. ❀



Photo: Chris Schwarz

Patients at St. Christopher's feel relief at being able to talk to doctors about non-medical problems.

In 1969, the Home Care Programme was begun, adding to the regular community services, at their request, extra time for listening and support, skilled suggestions for symptom control, and a 24-hour, 7-day-week on-call service.

Research into the best drugs for pain control began the same year, while counselling for particularly stressed and lonely families began in 1971. Studies to evaluate the work of the hospice began the day it opened.

A full education programme, including seminars, courses, and study periods at the Hospice for doctors, nurses, social workers, and chaplains, started within the first year, with the aim to spread knowledge and give encouragement to the few earlier charities and individuals already serving such patients nationally and, indeed, worldwide. Members of St. Christopher's staff have travelled, lectured, and written widely. An Information Service was opened in 1977. The staff maintain personal links with many countries.

### Expansion of the hospice movement

Hospice teams now exist around the world, and a whole new field of palliative medicine and care

is developing. The basic principles of symptom control, communication, and family support by a multi-disciplinary team have been interpreted in many different ways:

- The first home-care team with no back-up beds began operation in 1974 in New Haven, USA, with a full body of professionals and a large number of volunteers. The service enabled about 70% of the patients to remain in their own homes to the end. Now there are over 1800 home-care teams in the United States.
- An external team provided consulting in the wards of St. Luke's Hospital, New York for a time and a similar team began work in St. Thomas Hospital, London in 1977. This hospice/hospital interface has great potential for teaching and is the likely pattern for those countries that, for one reason or another, will not build the independent hospice unit.
- Use of the term *palliative care* rather than *hospice* was first adopted in Royal Victoria Hospital, Montreal, Canada. In the French-speaking world, the word *hospice* had come to imply custodial, or less than optimum, care. The programme there includes a small ward and home-care and hospital consulting teams—a pattern that has now been adopted widely.
- In Poland the traditional Polish multi-generation family and its living conditions leads Polish families, particularly in working class and rural areas, to commonly feel a strong obligation to care for their ill relatives. Many families choose to discharge their dying family members from the hospital and nurse them at home. A small group of parishioners, encouraged by Father Heinrich Pera, a chaplain and nurse from the German Democratic Republic, began visiting patients at home and has now grown to become The Association of Friends of the Sick with some 6500 members. Volunteers work under the supervision and guidance of physicians and nurses. A hospital for cancer patients at Poznan has now developed a palliative care team.

- In Kenya, where community and family care for the dying is a part of the traditional culture, there is still a need for adequate pain relief. Four persons vowed to develop a hospice appropriate to the local social, economic, and geographical situation. A single-storey, pre-fabricated building located on the campus of

Fr. Len Lunn is head of the group of chaplains at St. Christopher's Hospice. He has taken the time to reflect with us certain aspects of his work, and we excerpt some of his remarks below:

*Caring for the dying is more than a procedure or a skill to be learned. It is an attitude. A multi-disciplinary team is necessary, taking power away from doctors. Death makes us all humble—none of us know the answers. We learn together—the team and the patients.*

*One of the greatest pains of dying is the loss of control. The gospel must address this pain.*

*Dying is an extreme form of poverty, an incapacity to effect change. We help by walking beside. We, in turn, are helped by discovering our own poverty.*

*I am more about the work of the church here as a chaplain than I was as a parish priest. The church is so busy with activities that it doesn't have time to listen. If I were back in the parish I would be more involved in people's search for meaning. Here we open doors more to listen to people. We start by listening to people to help them identify the pain, the joys, then seek to respond, to walk beside them. The church needs to engage more in the secular.*

*The hospice ministry could teach the churches many things: the value of the individual, the nature of community. Hospitality and community are craved for by modern man. The churches have failed to meet that need and have become irrelevant.*

*A passage in the Anglican Common Book of Prayer says: "From sudden death, dear Lord deliver us." I understand that now. It is beautiful to see people put the pieces of their lives together and die in peace.*

Kenyatta National Hospital on land loaned by the Ministry of Health is the epicentre of the hospice work—counselling, training, and administration (see page 14). Dr Anne Marriman, recently appointed as Health Service Coordinator, and her team are currently setting up hospice centres throughout the country, training trainers to disseminate knowledge and skills and to establish small centres of hospice expertise throughout the vast area of Kenya, where transport is costly and difficult.

### **Networking among hospice programmes**

There are now over 350 hospice teams in over 40 countries, not including the United States and Canada (see map). St. Christopher's keeps in touch with these through a Hospice Information Service, which publishes a *Directory of Hospice/Palliative Care Service Overseas* and *The Bulletin*, a monthly newsletter sharing experiences, ideas, and information on palliative care from around the world.

St. Christopher's also sponsors a bi-annual international conference on hospice care. The most recent, held in London in May 1991, featured four days of workshops, seminars, and visits, led by a faculty of 50 persons experienced in all aspects of hospice care.

### **Financing hospice work**

Financing hospice work varies throughout the world. Most initiatives have relied heavily on grants and personal giving. St. Christopher's still obtains nearly two thirds of its income and all its capital needs in this way. The National Health Service (UK) now finances some units and teams, but its hospice contribution overall falls short of its 50% aim.

Other countries find support through central funding or insurance, but more money is always needed, and most hospices rely heavily on volunteer help. Whatever the financial needs, it is important to foster information sharing and good relations with relevant government authorities. Some churches have been involved, but more often in supplying staff and volunteers from among its members than financial support.

Faith and personal commitment have often had to make up for financial security in this pioneering phase.

## Hospice Care Worldwide



Courtesy of the Hospice Information Service, St. Christopher's Hospice (July 1991)

### Hospice ideals

A hospice team, wherever and however it develops, puts the patient and the whole family at the centre of its work and planning. Concerned with the relief of suffering, it concentrates especially on the needs of people with advanced cancer and motor neurone disease who have a limited time left.

Hospice teams have also looked more recently at the particular problems of people with AIDS. Persons with AIDS may need much help if they are to live as fully as possible until they die.

Much can be done by the hospice team to relieve pain and other symptoms and so to free each dying person to make his own choices and plans, perhaps to heal quarrels and misunderstandings and above all to pay attention to what has most importance for him, his own faith or questionings, his inner values and hopes. By reviewing continually their own search for meaning in life and death, the members of the team can help create a climate in which the patient and family can find their own strengths and do the same.

The often surprising growth that people achieve in the days and weeks before death leads hospice workers to object strongly to enactment of laws allowing death to be deliberately hastened. They also fear that such law would impose social pressures on the weak and dependent and lead them to feel that a quick way out would relieve others of the burden of caring for them.

Many hospice teams have no buildings of their own and either share accommodation or even use their own homes as a base. All aim for the patient to remain in his or her own surroundings as long as possible, and this can often be to the end. Where the hospice exists in a separate building, it is likely that a quiet room or, more often, a chapel will be an important element. This space allows space in everyday life for the dimension of the spirit and its importance at this time.

Those of us who have been in this work for many years have seen countless people find their peace before dying, often without words. \*

## SPIRITUAL PAIN

*The following is the text of a paper presented by Dame Cicely Saunders at the St. Christopher's Hospice Fourth International Conference, September 1987, and originally published in Hospital Chaplain (March 1988).*

Rene Leriche gave one of the best definitions of that elusive entity pain some 50 years ago. He wrote, "Pain is the resultant of the conflict between a stimulus and the whole individual"—a good definition for us, who are concerned with the whole person, with a whole experience suffered, endured, passed through, as the Shorter Oxford English Dictionary has it, trying to be aware of all aspects of the person and group involved.

In our care for the individual in pain we try to be attentive to the body, to the family, and to our patient's inner life.

For the body: we strive for growing understanding and expertise in symptom control, for due regard to appearance and self-esteem, with maintaining activity and independence and all that keep going something of normal life.

For the family: we have to be aware of the whole group and the understanding and support they need if they are to find and use their own resources and strengths. Sometimes we have to help the patient reassert his own place in that group, people may withdraw because of their own fears and the pain of watching someone else's distress, and others begin to behave as if the patient's place were already empty.

Somehow there needs to be enough security for communication to open up if sharing is to happen and choices are to be made. The whole question of helping people to face truth is one of the constant challenges in our task of enabling people to be themselves in as honest a way as they can, to find reconciliation, and to make their farewells. All this is not just a salvage operation but the chance for a creative moment.

For the essential person: we need to concern ourselves with work, interests, and

accomplishments, for so many people identify themselves with what they do. But there is more to consider than that. What are the inner concerns and values, what has deepest meaning, where is the spirit of this person focussed? If someone is able to lay down life with some degree of peace and satisfaction, if it is all to make some sense to him (whether or not he thinks it is the final end) where does he have to look? Is this indeed what we may call the spiritual dimension? and from that, define spiritual pain?

Here the dictionary gives some clues. *Spirit* is defined as the animating or vital principle in man, the breath of life. *Spiritual* is given as that which "concerns the spirit or higher moral qualities, especially as regarded in a religious aspect." Some people we meet have had long links with religious beliefs and practices, held to more or less faithfully. For many they offer support at the deepest level, though for others they may be instead a source of disquiet or guilt. The chaplains among us are constantly involved with these problems and with the various answers of our patient's different religions.

But *spiritual* surely covers much more than that. It is the whole area of thought concerning moral values throughout life. Memories of defections and burdens of guilt may not be seen at all in religious terms and hardly be reachable by the services, sacraments, and symbols that can be so releasing to the "religious group." The realization that life is likely to end soon may well stimulate a desire to put first things first and to reach out to what is seen as true and valuable—and to give rise to feelings of being unable or unworthy to do so. There may be bitter anger at the unfairness of what is happening, and at much of what has gone on before, and above all



a desolating feeling of meaninglessness. Here lies, I believe, the essence of spiritual pain.

### The search for meaning

Most of us have a desire to belong safely to something greater than our insecure and vulnerable selves. The search for a meaning to things that includes oneself has recently been shown in a nursing research study by Simsen (1986) to be the major concern of a group of hospitalized patients. She set out to ask whether patients brought spiritual resources to the experience of illness and hospitalization and whether they experienced spiritual need. She found that in her 45 interviews that patients were most willing to speak of their beliefs and that they were important to two thirds of her sample, though personal beliefs and practices were more important than institutional forms. When she analyzed a smaller number of in-depth interviews, the encompassing theme was a search for meaning. . . . So far as I know, her patients did not have a life-threatening illness, which is surely even more likely to stir such feeling.

Many people involved with dying patients and their families have found much help in Viktor Frankl's book *Man's Search for Meaning*. Writing from the extreme situation of a Nazi labour and extermination camp, he says, "The

hopelessness of our situation did not detract from its dignity or meaning." Not knowing what had happened to his wife, he finds a moment of deep fulfilment in thinking of her—even though he does not know if she is still alive. That love, finding its deepest meaning in his inner self, his spiritual being, is still undefeated. He believes meaning can be found in such love, but also in the memory of accomplishment, and even in suffering itself. If we are held in suffering, we then have responsibility for the attitude in which we suffer. He believes that no one can tell another what the meaning of his life should be, but that each must not only look back at achievements stored in memory but also seek out the questions that life is asking of him in the present.

### Facing meaninglessness

The Old Testament book of Job presents the classic sufferer, and a recent book by Kahn and Solomon has taken a fresh look at his desperate search for meaning in his own trials and in the whole mystery of unjust suffering. As they say, it is out of the whirlwind that enlightenment comes. The source of the pain itself was the source of revelation. Job "finds peace and maturation to levels which could only be attained after intense inner suffering." Because he faced it, he finally comes through.



Photo: Chris Schwarz

"For the family: we have to be aware of the whole group and the understanding and support they need if they are to find and use their own resources and strengths."

So how do we help others in their struggle to find a way out of the pain of meaninglessness? We come from such different backgrounds, our stories are radically other, and we do not have mortal illness facing us. Can we build some kind of bridge between us so that we can meet and help their search?

We start in concern for the body, with the freedom and space we can give by skills in symptom control and care for role and appearance; in the welcome to the whole family group and help in their search for their own resources—but what else should hospice care have to offer? Hospitality to our patients must surely include the

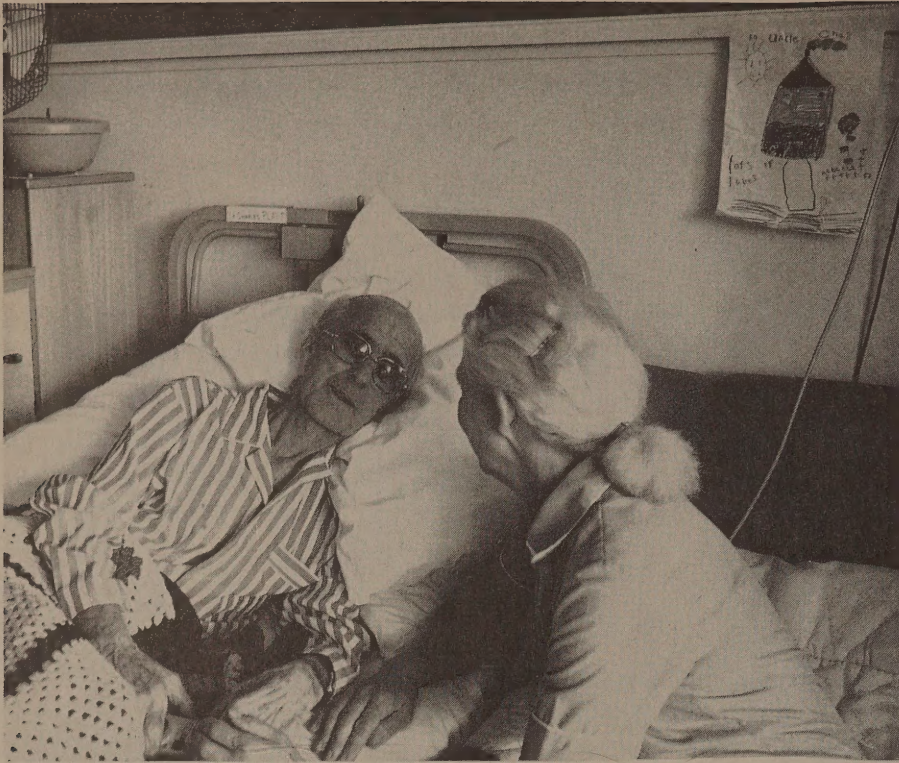


Photo: Chris Schwarz

"We have to learn to listen in a way that will help. . . to find the route to the real trouble and the way to handle it. Even to the end, the inner self can still stretch and broaden."

readiness to help them as they look at what is most important of all, their inner griefs, guilts, and longings. Jung (1959) refers to "the urge—often seen in those who are dying—to set to rights whatever is still wrong." That may still be a major need. Discussion will not always be appropriate and hospitality includes the right to privacy, but Simsen's study showed how eager most patients were to open up in this way and to face these matters.

It is a question of time—and timing—a readiness of the part of all staff to stop and listen at the moment this particular area of pain is expressed and to stay with it. We are not there to take away or explain, or even to understand, but simply to "Watch with me," as Jesus asked of his disciples in the Garden of Gethsemane. As we have worked so hard and so successfully to relieve physical pain and other symptoms, we may have been tempted to believe that spiritual pain should be tackled and solved in a similar way. Sometimes unrealistic fears can be explained and lead to resolution or a new vision, as came to Job. As Bishop John Taylor points out in his marvellous small paperback *A Matter of Life and Death*, the flowing of awareness and life into a numb and frozen limb is very painful indeed.

Only as a team becomes more experienced and confident do its members find it easy to allow or even encourage the expression of anger and other negative feelings that may express this inner pain, and the frequent question "Why?"

We have to learn to listen in a way that will help the complainer to find the route to the real trouble and the way to face and handle it. Even to the end, the inner self can still stretch and broaden. We neither have to idealize nor see the dark side only—but sometimes we need to look difficulties in the face and perhaps name them; that may well mean they lose some of their power to hurt or hinder.

### The need for a listener

But a search for meaning can take place more quietly than that. A volunteer who joined St. Christopher's at the beginning went round visiting in our men's ward for many years. An ex-headmistress, she spent her retirement in child care visiting, teaching literacy, and at the hospice. From this background she had developed an amazing facility for building bridges between the patients and herself. She told me that they never failed to find something in common, often some link with a happier past. From that—and also from their differences—she drew out parts of their story and listened as they fell into place and gave some final meaning to what they had found important. These were very private conversations but we gradually realized the depth of what she was doing. It was a way in which they could find the place where they could say, "I'm me—and it's alright."

This gift of listening to the story may be made by any member of staff but because they are often not concerned with any form of treatment, many volunteers and chaplains find they have a special place here. But we all have to listen. Not all are as unfortunate as he claims, but in ancient Rome, Seneca complained, "Who is there in all the world who listens to us? Here I am—this is

me in my nakedness, with my wounds, my secret grief, my despair, my betrayal, my pain which I can't express, my terror, my abandonment? Oh, listen to me for a day, an hour, a moment, lest I expire in my terrible wilderness, my lonely silence. Oh God, is there no one to listen?" He is not asking for more than a fellow human being to stay there. This is the need of those who are dying and sometimes, even more poignantly, the bereaved.

A short time of true attention can reach such bitterness and quieten such angers and fears. Answers are not really expected and long sessions are not always needed. Old structures and values can emerge almost unbidden to make sense again, and sometimes new discoveries develop from the interchange with a committed person. As a patient said, "I thought it so strange. Nobody wants to look at me. And then, doctor, I came here and you listened to me. I felt you understood. It seems the pains went with me speaking to you!"

The often simple exchange that arises in such meetings may be felt as a gift. But we are not the only givers. Sooner or later all who work with dying people know they are receiving more than they are giving as they meet endurance, courage, and often humour. We need to say so, recognizing, too, the common conviction that there is an enabling grace coming in from beyond us both.

We are not alone in these sometimes very taxing situations. Like Job, our patients may find unexpected resources and new self-awareness and life growing up within themselves once they accept the mystery and the inadequacy of our human sense of justice and desert. Life is not fair, there are no easy answers, but there is a way to acceptance and peace for the last part of the journey.

Sometimes we will see this happen in terms of our own beliefs and a structure of simple ward prayers can be helpful and is not obtrusive, but only when asked are we called to share more personally. But unless we are occupied in our own search for meaning we may not create the climate in which patients can be helped to make their own journeys of growth through loss.

### **Sharing in the silence**

It is hard to remain near pain, least of all an anguish for which we feel we can do

nothing. . . . Job's friends are often criticized, but as Kahn points out, they came together to him, they rent their garments in a gesture of solidarity, and they sat down on the ground beside him for a long time in silence. Only after Job himself began to speak did they bring forward their inadequate answers. And it was partly in indignation at them that Job begins to dig deep into his own pain and finally comes face to face with a vision of God that leaves him in a new humility that accepts his human condition and all its mystery.

If we are Christians, our vision is of God's sharing with us all in a deeper way still, with all the solidarity of His sacrificial and forgiving love and the strength of His powerlessness. As Bishop Taylor wrote in a Christmas poem, "I am the undefeated heart of weakness." That loving power will outlast all else and holds out an ultimate hope of life through death.

Sometimes we can speak of this, more often we have to stay silent beside this silent God whose ways of meeting each person's need will so often be known to them alone. In our turn, we have to trust in the often perplexingly anonymous Spirit. Many hospices have chosen a free flying bird as their symbol. For us, this represents the Holy Spirit, but I believe this echoes the many religions who have spoken of some form of inner guide or way-shower. . . .

### **Persevere with the practical**

But many of us have little or no opportunity for the time these interchanges may call for—our patients are too ill and we are sometimes too busy. That, too, we often have to accept, but we can always persevere with the practical. Care for the physical needs, the time taken to elucidate a symptom, the quiet acceptance of a family's angry demands, the way nursing care is given, can carry it all and can reach the most hidden places. This may be all we can offer to inarticulate spiritual pain—it may well be enough as our patients finally face the truth on the other side of death. Our own pain will be easier to bear if we can hand on quietly what we have given and hope that it will be used and, in our turn, continue our own search for meaning, for acceptance of our own story, and our place in a creation that is ultimately good and to be trusted. ✱

# SYMBOL OF HOPE—NEW GREEN LEAVES SPRING FROM A WITHERED TREE

## The Hospice of Yodogawa Christian Hospital

*by Dr Tetsuo Kashiwagi, Vice Superintendent,  
Director of Hospice, Yodogawa Christian Hospital, Osaka, Japan*

In the summer of 1973, a patient at the Yodogawa Christian Hospital began suffering severe pain from recurrent rectal carcinoma. The physician in charge recognized that he could not meet all of the needs in this man's life and illness and so called upon the hospital psychiatrist to continue the work in line with the hospital's aim to treat the "whole person."

Deep concern for this case triggered the creation of a programme of Organized Care of the Dying Patient (OCDP)—the first of its kind in Japan. Physicians, nurses, social workers, paramedical staff, and members of the chaplain's department met together at least once a week to discuss how to meet the wide range of needs of their patient's with terminal illnesses. Their work was to touch on many aspects of the lives of patients and their families.

The hospital staff realized that the patient who is often lonely and in pain shows one face to his doctor and quite another to his family or another member of the hospital staff. Thus it became important for team members to give special attention to the patient's reactions and feelings and, in turn, to communicate as necessary with other team members. The multi-disciplinary team began sharing with patients and among themselves.

Over the early years of the programme, Yodogawa staff found that family members of patients often felt that their apartments or homes were too small to provide adequate care for loved ones suffering from terminal illnesses. The need for a facility expressly for the care of such patients became more and more obvious. Gradually a plan evolved for setting up a

separate unit for a hospital-based hospice. Upon reconstruction and enlargement of the hospital, the entire floor of one wing of the building was designed to meet this need.

Located near the bullet train station in the industrial metropolis of Osaka, the Yodogawa Christian Hospital has grown over its 32 years from 60 beds to 388. It treats some 1000 outpatients daily. It is a modern, well-equipped medical facility dedicated to the glory of God and the salvation of man through the ministry of healing. As a non-profit institution, Yodogawa seeks to provide comprehensive medical care using a team approach in the treatment of the whole person. It is the aim of the hospital to correlate the power of Christ's love and the highest quality of care offered by modern medical science in caring for the social, physical, mental, and spiritual needs of its patients. Thus it was appropriate that such an institution would have a special concern for helping patients in the terminal stage of illness.

In April 1984, the Hospice of Yodogawa Christian Hospital admitted its first patient, a minister who had been a patient in the hospital. He had already been under care by the OCDP team for some time. This patient and those who followed him have shown that loving and caring for people enriches both patient and caregiver.

### **The Yodogawa approach**

Serving a 23-bed unit, the hospice staff is composed of 3 doctors, 19 nurses, chaplains, medical social workers, and volunteers. The hospice team tries to spend as much time as possible with the patients, sitting and listening, talking with eye-to-eye contact, or simply sitting

together quietly with a caring attitude, giving comfort by just being there.

Family relationships in Japan are traditionally very close, and it was essential for hospice care to be a cooperative effort between the patient, the family, and the medical staff. The new hospice care unit was planned with family involvement in mind and included beds for family members to sleep near the patient if they wished, an eight-mat Japanese-style family room, a kitchen for preparation of the patient's favourite foods, a room for conferences between medical personnel and the family, a chapel for prayer and small meetings.

The hospice team worked on many details in an effort to provide a warm, friendly atmosphere in the spacious facility with good lighting and rooms open to sunlight. Upon entering the hospice, one immediately sees a large, comfortable central lobby where patients and staff, family members, and visitors can relax at any time. Adjacent to the lobby is a terrace, planned to incorporate the four things most important to a Japanese garden: stone, water, green plants, and fish. Patients in wheel chairs and even in beds can go out on this terrace in the sunshine by a small car pond, with a view of the terrace garden, city, and distant mountains.

A tea party is held in the lobby each afternoon for patients and their families. Patients in wheelchairs and beds are rolled in to join the ambulatory patients. There are monthly special

programmes and occasional concerts (violin, flute, guitar, vocal), special exhibits and patient/staff arts and crafts exhibits, Christian messages, and Christmas and Easter programmes. Birthdays are celebrated with singing, and warmth is expressed in small, caring ways.

On the terrace is an emblem with the hospice logo showing a patient being supported by a representative team of hospice staff. Below are the words "we care." Such care of course includes pain and symptom control, in consultation among patients, families, and staff. Almost all of the hospice patients are ill with cancer. Morphine given orally is the key analgesic in use. Both doctors and nurses give their utmost in the control and pain and good bedside care, continuing to work together to best meet the needs of the individual patient.

A medical social worker, after visiting in some of the patients' rooms, observed: "I had had a gloomy image about the hospice, but I have changed my mind. The hospice is so bright and open. I especially noticed that the nurses there are working with such a beautiful and joyous attitude. This is marvellous!" Staff shared with her a Bible verse that is especially meaningful to them: "Whoever would become great among you shall be servant of all" (Mark 10: 44). Scriptural verses meaningful to both patients and staff are passages in the Psalms, especially Psalm 23. Romans 15: 12, 13 are verses that speak of hope.



Birthdays at Yodogawa are celebrated with singing, and warmth is expressed in small, caring ways.

The window in the hospice's small chapel is a symbol of hope, especially the hope of the new life that is in Christ. It shows an old stump, supported by hands. New green leaves have sprung from the stump. We read in Isaiah 11:1 that "a shoot will come up from the stump of Jesse; from his roots a Branch will bear fruit."

Despite the Christian orientation of the hospice, a large number of the patients are not Christian, nor are they pressured to become

Christian because they are being cared for in a Christian hospice. Nevertheless, through the years, a number of patients have found hope and meaning in the Christian faith and have asked to be baptized. A favourite hymn among Japanese patients, both Christian and non-Christian, is "What a Friend We Have in Jesus," which expresses in Japanese a deeply comforting concept.

We feel that for anyone interested in beginning a hospice project, it is extremely important to set up a staff team of people who are mature, responsible, and caring; who have a sound view of life backed with faith—persons who are able to deeply comprehend the quality of life, which in turn gives quality to the lives of others.

Because the Japanese are sometimes called a "death-denying society," we have publicized the need for physical, mental, social, and spiritual care for terminally ill patients through books, newspaper and magazine articles, television interviews, and participation in conferences and seminars on this subject. In the beginning the response to the hospice concept in Japan was mixed, but in recent years it has been arousing a good deal of interest among the general public and in medical circles. During the last decade, a number of study groups have been formed and several hospice or hospice-type programmes opened.

Support from the Church throughout Japan—through its interest, prayer response, and donations—has been encouraging.

The expense of medical care in the hospice is covered basically by the medical health insurance system, but there is no special subsidy for the additional quality staff time and attentive care offered by the hospice. The balance of costs is covered by donations from churches and contributions from individuals, groups, and families of former patients. Many of the strong hospice volunteer workers come from local churches.

There is considerable drama lived within the walls of the hospice and in the lives of terminally ill patients and their families. With its continuing emphasis on compassion and the value and quality of life, the Yodogawa hospice is a significant opportunity for service that can have far-reaching impact in Japan. ❀

## A DAUGHTER-IN-LAW'S HOSPICE EXPERIENCE

Our overseas trip had been long planned when my husband's mother showed signs of recurrence of cancer. We contacted the local hospice service [of the Geelong Hospice Care Association, Australia]. Although mother was still capable of caring for herself, they offered to keep a "friendly watch" over her during our absence, so we went away with a degree of confidence we would not otherwise have had.

On our return, it was clear that her health had deteriorated, so it was arranged for her to leave her home and move into ours. The hospice service started calling on a regular basis, and other friends supported me in various ways. The hospice service provided a water-filled mattress, a bedside chest, and an over-bed pull bar. We were able to transform one of our bedrooms into a kind of hospital ward.

These arrangements were working well, when mother suffered a leg fracture and underwent surgery. Two weeks later, she was home with us again, but completely bedridden. The hospice nurses began visiting more often. Mother could not be left alone, but I was able to use the time during their visits to attend to shopping or business. At night and on weekends, my husband took over her care.

It was on a Saturday afternoon that we realized that mother's death was near. We called my sister-in-law. The next morning, mother died peacefully, with her children by her side, in our home. We took our time to say goodbye, and, when that had been done, we called the funeral director.

I am not a trained nurse and could not have cared for my mother-in-law at home without the expert help offered by the hospice service. As it was, she was able to die in familiar surroundings where we could offer her the love she deserved and where we were free to make our parting at our own pace.

Helen (July 1991)

# PALLIATIVE CARE IN AUSTRALIA

By Trevor Banks \*

The secular and hedonistic nature of Australian society offers a wonderful opportunity for the application of hospice principles. Hospice care affirms the worth of people and treats their illness as a total experience. Intentionally or unintentionally, to enter into the area of relationships is to confront the spiritual issues of life. And in caring for dying people, existential questions frequently arise. Australian palliative care may be predominantly secular, but it is also helping to deal with deeper issues and acting quietly to change health care delivery.

Australia is regarded as the most urbanized country in the world, with the majority of the population living in the five largest cities. Even in the state with the highest population density, Victoria, there are areas where health service delivery is reduced by distance and low population density. This leaves the rest of the population widely scattered and without services. Such an area, Geelong, is served by a home care hospice service, which provides visiting nurses, volunteer support, and medical consultancy.

To encourage the development of services to give palliative care coverage in more remote areas, a Regional Palliative Care Program was established in 1989. This programme has given a much higher profile to the care of terminally ill people over a large area. It has given added confidence to visiting nurses, who know there is a nurse consultant to whom they can turn for advice and support. It has enabled direct contact, by the palliative care medical officer, with family doctors in order to strengthen the

home-care base. It is encouraging training of lay volunteers to support families in the home. It both encourages and facilitates home-care of terminally ill patients.

One evidence of how important the hospice movement has become in Australia is the degree of development of education on the subject. Flinders University (South Australia) has a Professor of Palliative Care and has instituted a Masters programme in health studies with a palliative care component.

In Western Australia, there is a three-month intensive multi-disciplinary course conducted at Cottage Hospice. Curtin University also offers a multi-disciplinary course.

Other states offer diploma courses in palliative care for nurses, but medical education is not as well developed. Local initiative has resulted in informal education on palliative care.

Research in palliative care is yet limited, but papers presented at Hospice '90, a National Conference, held in Adelaide in October 1991, showed broad interest in research. In Adelaide and Brisbane, new work has been done on the pharmacology of morphine. At the government level, reports have been commissioned on care of the the dying and palliative hospice services. These reports are helping to shape the nature of service delivery.

One of the striking features of Australian society is its multi-cultural composition. To date, palliative services have been most readily received by the (Anglo-Saxon) predominant culture group. Language barriers and cultural differences in the understanding of death among various groups of Australian society will be important considerations for the work in the next decade. \*

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\* Dr Banks, M.B.B.S., is a full time Palliative Care Medical Officer and adviser in Palliative care at Geelong Hospital, Australia.

# LIVING WHILE DYING

*by Anne Merriman, Health Service Coordinator,  
Nairobi Hospice, Nairobi, Kenya*

John was a patient referred to the Nairobi Hospice in November 1990. He died in May 1991. John had been in and out of hospital for several months before he was referred to us. After the hospice took over his care, he lived with his young family and continued to supervise the building of his house until a few days before his death. He was never admitted to hospital again. He told us, "Before I met you I was dying . . . . Now I am living."

John is one of 180 patients who have been cared over the last year and a half by the Nairobi Hospice, mainly at home. The ages of these patients ranges from two to ninety, although the average patient age is below that of hospice patients in the United Kingdom. Often cancer is very advanced when first seen, and patients suffer psychological pain due to changes in appearance, from advanced cancer of the face, for example.

The hospice idea is new to Kenya, and ours is only the second hospice foundation in sub-Saharan Africa. We therefore have an extensive teaching programme reaching out to doctors, nurses, and volunteers in Nairobi and the provinces. Our aim is to bring pain, symptom control, and provide psychological support to all those in need throughout Kenya.

Our hospice care is provided free of charge,

but most of our patients cannot even afford their medication. Our problems include meeting the costs for these patients, and at the end of 18 months service we are greatly in need of funds to continue the work.

We are presently concentrating on consolidation of the hospice in Nairobi and the training of Kenyan staff. We hope to have a doctor in training by next year. Following this, we hope to help other provinces to set up hospices. Already there has been interest shown in Nyeri, Nakurru, and Mombasa.

As this is very much God's work, we are putting our trust in Him to continue what was begun with the courage of those who saw a need and established the Nairobi Hospice to meet it. ✱



Dr Anne Merriman, with a grateful patient, Maria.



The Centre for Continuing Care of the Cantonal Hospital, Geneva, Switzerland has a special ward to care for terminally ill patients. A unique aspect of the programme is regular commemorative services to help the staff to deal with their grief over the loss of so many patients. Chaplain Cosette Odier plans the service to encourage the telling of stories of patients who have recently died and the free expression of feelings that the stories release. These services have been especially helpful to doctors, often trained to be unnaturally "objective" in their relationships with patients.

Rev. Odier works as much with staff as with patients, mostly to listen and accompany—"not so much to bring the good news as to recognize it, name it, and give confidence to those involved," she explains. By sharing her feelings she allows other team members to do the same, and, together, patients and the hospital team receive healing.

In this programme not only all hospital staff from aide and interne to director-general are considered important in their relation to the patient, but others as well such as close relatives, friends, employers, and pastors. Communication with the patient is consistently enhanced through this network of relationships.

Truly I tell you;  
anything you did for one of my  
brothers here,  
however insignificant,  
you did for me.

Matthew 25: 40  
(Revised English Bible)

## THE CHURCHES' COUNCIL FOR HEALTH AND HEALING

Through the vision and effort of Anglican Archbishop William Temple, the Churches' Council for Health and Healing (CCHH) was founded in London in 1944 to help bring Church and medicine together. Since that time, great strides have been made in reaffirming the Christian healing ministry in response to Christ's command to preach the Kingdom and heal the sick, in partnership with the medical profession.

CCHH is a Christian ecumenical health and healing coordinating agency comprised of:

- 29 Christian denominations
- healing guilds and associations
- Christian healing trusts and healing homes
- the Hospital Chaplains' Fellowship
- the Royal Colleges of Medicine, Nursing and Midwifery
- the British Medical Association
- the British Dental Association
- other Christian organizations actively concerned with healing.

CCHH calls itself an "umbrella organization," coordinating, facilitating, informing, encouraging, guiding, and supporting member organizations in their work. It explores the theological and pastoral problems raised in the context of modern medicine, church healing ministries, chaplaincies, and healing homes and shares the findings with its constituency.

CCHH has close links with the Churches' Council for Britain and Ireland, CMC, the German Institute for Medical Missions and the Christian Medical Association of India.

A joint working group of CCHH and the Royal College of General Practitioners produced a booklet entitled *Whole Person Medicine* in 1989. Later, responding to a British Government White Paper on health, a CCHH committee produced a paper on how the Christian concept of health could be incorporated into the National Health Service. The organization also produces training videos on various aspects of healing ministry.

A list of publications and papers and a list of member organizations is available from CCHH (see address list on back cover). \*

## WHO AND PALLIATIVE CARE

As part of its programme on cancer and palliative care, the World Health Organization (WHO) is actively involved in improving care for the dying. Specifically, WHO is pressing for the availability of appropriate drugs to keep pace with improvements in the knowledge and application of cancer pain therapy.

Programme chief Dr Jan Stjernward notes that "effective control of cancer pain remains an urgent public health problem in most countries throughout the world. At a conservative estimate, at least four million people are presently suffering from cancer pain, the majority of whom still receive inadequate relief.

"It is important that we mount a vigorous programme to initiate and continue a dialogue with drug regulatory authorities and government officials."

The booklet **Cancer Pain Relief and Palliative Care** is a comprehensive report by the WHO expert committee on the subject. It argues that palliative care, which seeks to control pain, manage other physical symptoms, and provide psychosocial and spiritual support, should be an integral part of cancer care.

Available in English and French (with Spanish in preparation) at SFr 9 (SFr 6.50 in developing countries) from WHO booksellers or directly from WHO at the following address:

Publications Distribution and Sales  
World Health Organization  
20 Avenue Appia  
1211 Geneva 27  
Switzerland.

## USEFUL PUBLICATIONS

**Living with Dying: the Management of Terminal Disease** by Cicely Saunders and Mary Baines

When it becomes apparent that treatment for fatal illness is no longer effective, the alternative is not simply "custodial care." To practise skilful medicine for the terminally ill is both demanding and rewarding. Reading this book will help you do it well. Out of their long experience and research, the authors inform not only on the ethical principles involved but equally competently on the control of pain and other symptoms. Anyone working with sick people would benefit from reading this book.

Available at £9.50 from St. Christopher's Hospice (see back cover for address).

**Hospice and Palliative Care — an interdisciplinary approach**, edited by Cicely Saunders

Not intended as a "how to" book, this is rather a sharing of what has become over the years a challenging and supportive way of working as a team with dying patients. Physicians, nurses, chaplains, social workers, physiotherapists, and registrars have cooperated to set out the tensions involved in the challenging and demanding field of palliative care.

The first half of the book deals with team work and what makes it happen. The second half offers case studies illustrating dilemmas that can arise in palliative care and showing why team work is so important in relating not only to dying patients, but to their relatives and friends.

Available at £8.95 from St. Christopher's Hospice (see back cover).

**First Do No Harm** by Bruce Hilton

Sooner or later, all of us will be confronted personally by one or more of modern medicine's dilemmas—whether to turn off the ventilator, order a test for trisomy, or undergo a transplant or a surrogate pregnancy, for example. This book provides no ready-made answers but prepares us, through case studies that raise the questions, to think them through for ourselves, before a crisis strikes. Good reading for all who want to make their own well-informed decisions.

May be ordered from:

Abingdon Press  
201 Eighth Avenue South  
Nashville, TN 37202  
USA

**The Healing Brain** by Robert Ornstein and David Sobel

This is a scholarly but very readable account by a neurologist and a preventive medicine physician of the breakthrough discoveries of how the brain keeps us well. It provides important insight in the reconciliation of scientific medicine and "faith" healing. The authors document the powerful influence of beliefs held by the community and world on our health. Top priority reading for anyone interested in health, healing, and wholeness.

May be ordered from:

Simon & Shuster  
1230 Avenue of the Americas  
New York, NY 10020  
USA

**The Faith Factor in Healing** by Thomas A. Droege

Setting out to bridge the gap between medicine and faith from the side of faith, Tom Droege, a professor of theology, spent a year at Stanford Medical School. There he gained insight into the importance of our life stories in illness and health and how relating this to the Gospel can be health giving, especially through the use of imagery in meditation. An important resource book for those seeking to understand the connection between faith and health.

May be ordered from:

Trinity Press International  
3725 Chestnut Street  
Philadelphia, PA 19104  
USA

**The Challenge of Christian Healing** by Stephen Parsons

This book is about the "throwing away your crutches" kind of healing. It is a remarkably balanced, comprehensive, and credible account based on personal experiences, with extensive interviews with those involved. It covers healing by individuals, sacramental

healing, and congregational healing services and concludes with a "theology of healing." Recommended for all who would like to know more about the gift of healing and how it is being used in the world today.

May be ordered from:

SPCK  
Holy Trinity Church  
Marylebone Road  
London NW1 4DU  
United Kingdom

## CMC NOTES

### Medicine and Theology—can they get together?

CMC and the Ecumenical Institute announce a seminar to be held from 13-23 May 1992 at the Ecumenical Institute, Bossey, Switzerland.

A major message from the ten CMC-sponsored regional consultations on health and healing was that there is a continuing but urgent need to develop the dialogue between medicine and theology. The two disciplines speak different languages, view the human being differently, and are often intimidated by one another. A Czechoslovak physician and participant in the consultation held in Budapest remarked that today's need is to "reinterpret the gospel for medicine; as Bonhoeffer did for politics."

This seminar is open to those interested in the interface between theology and medicine and in developing ideas and mechanisms for dialogue towards a common understanding and practice of health. Preference will be given to those with experience, but an effort will be made to obtain global, gender, and ecumenical balance. Pedagogy will emphasize participation—all participants will be considered resource persons.

Cost, including board and lodging is SFr 710. A limited number of scholarships are available for participants from developing countries. For information or application forms, please write to:

Programme Secretariat  
Ecumenical Institute  
Château de Bossey  
1219 Bossey  
Switzerland.

## USEFUL ADDRESSES

### Australia

The Affiliation of Australian Palliative Care  
Hospice Programs  
P.O. Box 275  
Belair SA 5052

### Canada

Canadian Hospice Association  
c/o Royal Victoria Hospital Palliative Care  
Service  
678 Avenue de Pins Ouest  
Montreal H3A 1A1

### Great Britain

St. Christopher's Hospice Information Service  
c/o St. Christopher's Hospice  
51-59 Lawrie Park Road  
Sydenham  
London SE26 6DZ

The International School for Cancer Care  
c/o Mr. R.C. Whittet  
25 New Road  
Digswell  
Herts AL0 0AQ

National Hospice Council for Palliative and  
Specialist Services  
c/o St. Christopher's Hospice Information  
Service  
(See address above)

The Churches' Council for Health and Healing  
Revd David Howell, Acting Director  
Marylebone Parish Church  
Marylebone Road  
London NW1 5LT

### Japan

Dr Tetsuo Kashiwagi  
Vice Superintendent  
Director of Hospice  
Yodogawa Christian Hospital  
9-26 Awaji 2-Chome  
Higashi Yodogawa-Ku  
Osaka

### Kenya

Nairobi Terminal Care Centre  
P.O. Box 74818  
Nairobi

### United States of America

The National Hospice Organization  
1901 North Moore Street  
Suite 901  
Arlington, Virginia 22209

### International

European Association for Palliative Care  
c/o Professor V. Ventafridda  
Istituto Nazionale dei Tumori  
Via Venezian 1  
20133 Milan  
Italy

Dr Jan Stjernsward  
Chief Medical Officer  
Cancer  
World Health Organization  
Avenue Appia  
1211 Geneva 27  
Switzerland

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